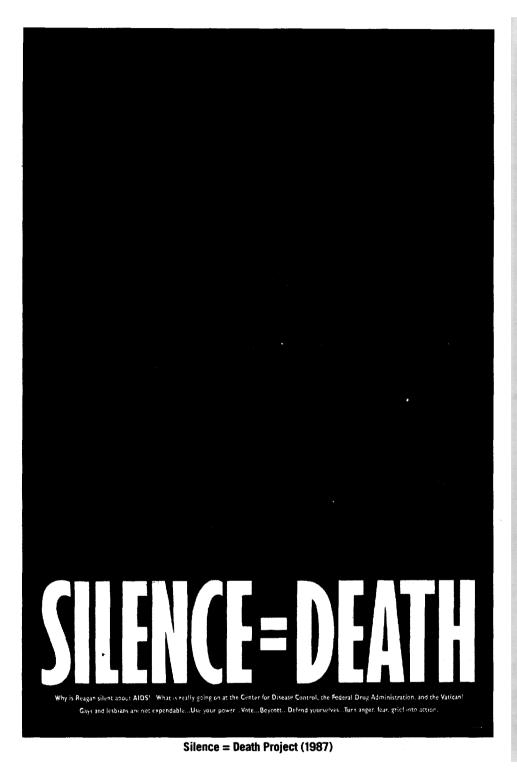
Act up: 10 years and counting--The AIDS shock troopers who changed the world

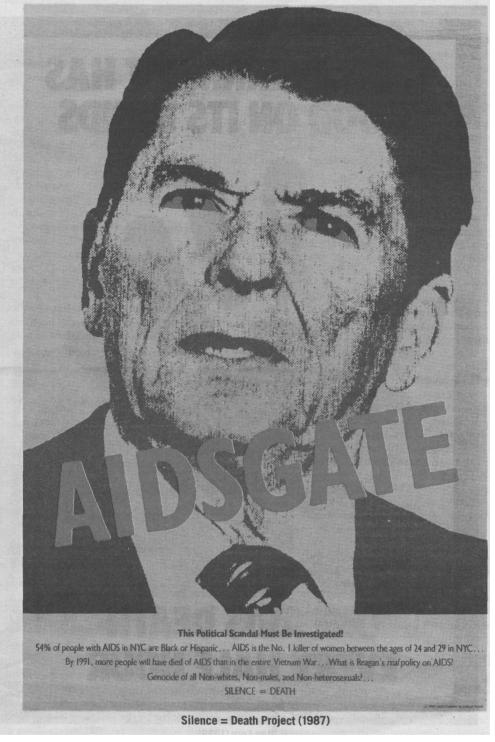
Schoofs, Mark

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ACT UP: 10 YEARS





THE AIDS SHOCK TROOPERS WHO CHANGED THE WORLD BY MARK SCHOOFS

Conference in Montreal, ACT UP was "marching around in our little circles," remembers Ron Goldberg, who is writing a book about the group. "But someone said, 'Look, the doors are open!' So we went in and started marching around in our little circles again. And then, suddenly, everyone started going up the escalator and marching down the main aisle of the conference and commandeering the stage.

We were there before we knew how or why."

Always ready to improvise, ACT UP used this opportunity to read a bill of rights for people with AIDS, which received a standing ovation from the crowd of scientists. Then the activists sat in the seats that had been cordoned off for VIPs. "They didn't like that," says Goldberg, "and they tried to move us. But it finally dawned on them: Oh, people with AIDS are the VIPs."

Founded by Larry Kramer with a fiery speech, and named by his audience afterward, ACT UP turns 10 years old this month. To mark the occasion, the group plans a march on Wall Street next Monday, March 24. Some say ACT UP's time has passed, but even if that's true, its legacy exceeds the sum of the victories it helped win: faster drug approval, protection against discrimination, needle exchange in various states and cities, and hundreds of small improvements in services and care.

At its height, there were more than 60 ACT UP chapters across the U.S. and many more around the world.

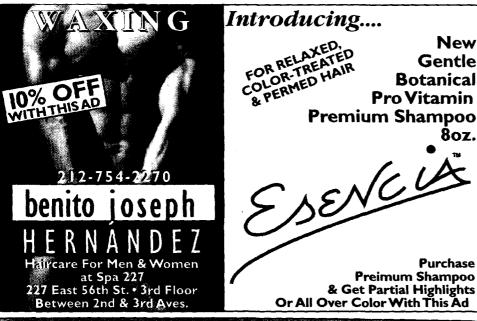
Like the proverb about teaching the hungry to fish rather than merely handing them food, ACT UP taught patients to take charge of their care, and in so doing changed them from victims to VIPs. "Never before," says Peter Staley, an early member of ACT UP, "had patients been accepted as equal partners in finding a cure for their disease."

To achieve this, ACT UP had to battle the medicalindustrial complex, which accounts for one-sixth of America's gross national product; the tradition of science as an
ivory tower open only to experts; and, most fundamentally,
the notion that sick and dying people cannot be strong. But
AIDS patients, sometimes emaciated or in wheelchairs,
stopped traffic on Wall Street and the Golden Gate Bridge,
infiltrated the Food and Drug Administration and the set of
CBS News, heckled corporate executives and the president
of the United States, and burst onto every front page and
TV screen and ultimately into the popular consciousness.

"Someone 25 years old, gay or straight, with AIDS or not, has a different CONTINUED ON PAGE 44

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SCHOOFS

CONTINUED FROM PAGE 42 view of their doctor than they would have 10 years ago," says Sean Strub, founder and editor of the AIDS magazine POZ. "There's a reason ACT UP never incorporated, never sought to build a staff. The idea was not to build an institution with a budget and a bureaucracy. The objective was to change people's relationship to the epidemic and the health care system in general, to make us all players. To analyze its impact, don't look at how many people show up at ACT UP's meetings. Look at how many people took ACT UP's values into their lives."

he reason ACT UP came into existence," says activist Ann Northrop, "is because people who thought they had power-young white gay men—threw a tantrum when they found out no one cared if they lived or died." Their fury was mixed with faith in the system. "This was the generation that grew up watching men going to the moon and believing in the American dream," notes Mario Cooper, a black AIDS activist. "They didn't believe anything was impossible." Indeed, says Strub, "We thought we were going to find a cure. We really did?

Julian Bond compares ACT UP to the Student Nonviolent Coordinating Committee, the civil rights group he helped lead. Like SNCC, ACT UP drew young people "with a kind of in-your-face, we-want-this-right-now attitude." Such "confrontational tactics," he says, always frighten the horses: "In the women's movement, the more aggressive suffragists were chaining themselves to the White House fence while others were saying, 'Oh dear, that's not how women act!' It was the same thing with SNCC, and, I suspect, with ACT UP.

Strub remembers how some of his friends dropped him because of his involvement with ACTUP. But, he says, "all these people who are alive now owe it to some black-booted, ring-inthe-ear queer screaming his lungs out on the street 10 years ago."

here was more than rage in that screaming. Cultural critic Douglas Crimp has written that ACT UP gave gay men an outlet for the mourning society denied them.

"That's right," says Marcus Conant, a San Francisco physician who was one of the first to treat people with AIDS. As his patients died, Conant often witnessed homophobia trampling on gay grief. "One scene stands out in my mind," he says. "The father and his wife have flown in to visit their dying son, who is clearly never going to get out of that hospital room. The other person there, standing in a corner, is the dying man's lover of 22 years, who is grieving because he's about to lose his lover but also because he knows he will die in exactly the same way. That's something a lot of people don't understand, the courage and pain of taking care of your lover when you know the same fate awaits you. Anyway, the father takes the lover out to the waiting room, shows him old snapshots of his son with a beautiful woman, and says to the lover, 'If he had just married Betty Sue, this wouldn't be happening.'

s any soldier can attest, living close to death fuels not only rage but humor. And ACT UP, with its predilection for camp, was often very funny. In 1988, the Reagan civil rights commission decided to hold hearings on AIDS discrimination, but with a twist. "The whole thing was jiggered to the rights of property owners who had to house people with AIDS, author Ron Goldberg remembers. "The plan for the hearing quoted Biblical sanctions against homosexuality. We didn't want to give it credibility by testifying, so we were racking our brains to come up with some way to disrupt the hearing. I mean, we were thinking of letting

mice go in the auditorium."

What did they finally come up with?

"'Send in the Clowns'," Goldberg giggles. A contingent of demonstrators took seats in the audience and, when the session began, donned clown masks adorned with fluorescent orange hair. "The moment we put on the masks, all the lights and cameras swooshed away from the commission and focused right on us." This mixture of political theater, gay style, and dead-on politics made ACT UP the most memorable and effective activist group since the '60s.

There were mistakes. At the 1990 International AIDS Conference, ACT UP was angry with Louis Sullivan, the secretary of health and human services under Bush. The group drowned him out. Such censorship contradicted ACT UP's oft-stated intention to empower people with information—and probably was a tactical error. The 1989 action at St. Patrick's Cathedral, where an ACT UP member defiled the communion host, cost more public support than it gained. But the scandal, says Goldberg, gave us a certain amount of threat capability: 'Oh my God, what are they going to do next?'

Sometimes, that frightened off the wrong people. "A major drug company told me, We're not going to do any work on AIDS drugs because of the activists," says Conant. "They were not willing to deal with being singled out for attack."

Some of the group's aggression got expressed in infighting. "We had to fight against white boys' arrogance and racism," says Keith Cylar, one of the most active African Americans in ACT UP. Meanwhile, many white gay men thought identity politics was diverting attention from the goal of finding a cure. "A lot of people were more concerned with making a political statement than doing something about the lives of people with AIDS," says treatment activist Spencer Cox.

"In the early years it was wild, loud, and argumentative, but it was family," says Staley, who left his job as a bond trader when the stock market crashed-"and so did my T-cells." He saw ACT UP grow from a small cadre. "When we attained a certain level of notoriety and power, the crazies came flooding in and made it down-right miserable at times." Undercover police also contributed to the acrimony, as did an ever more intense factionalism.

And people kept dying. Mark Milano, an ACT UP member since 1988, estimates he has heard nearly 100 "obituaries from the floor," the eulogies ACT UPers gave for their own. Goldberg remembers "a particularly brutal week" in November 1990, when four prominent members of ACT UP died. "There came a point when so many people were dying," says Kramer, "that it began to have a depressing effect. People started turning on each other, rather than on the system. And when ACT UP became increasingly unpleasant, that's when the splitting off happened."

Dozens of top activists left to work with

other AIDS agencies, many of which grew out of ACT UP. Indeed, another ACT UP legacy is the scores of organizations it spawned, including Housing Works, the gay magazine Outweek, Treatment Action Group, and the Lower East Side Needle Exchange. "ACT UP was a university," says Strub, and its graduates now staff the top ranks of many AIDS and gay organizations.

"ACT UP's legacy is probably what they would hate the most," Cox says drily. "It trained a whole generation of people to work in nonprofits—to get up in the morning, get dressed, and do the work."

hree hundred people used to come to ACT UP every Monday night, but fewer than one-fifth that number attended last week's meeting. The group has dwindled to "a small number of people who are very devoted but relatively powerless," laments Kramer.

You don't need thousands of people at a demo," counters Milano. "Just a small strike force can make a difference." Last April, Milano and three other activists targeted Stadtlanders pharmacy. Why? The pharmacy had exclusive rights to sell one of the new protease inhibitors, and it was

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charging a 40 per cent premium to people who paid cash—in other words, to people without insurance or Medicaid. "We plastered the front of the store with 'AIDS Profiteer' stickers, got arrested, and spent 28 hours in jail," Milano recalls. "The next day Stadtlanders reduced the price."

Other groups helped ACT UP push Stadtlanders, which is why "we need players on the inside, cutting backroom deals," says ACT UP veteran Eric Sawyer. "But we also need people on the outside who can be the unrestricted conscience of the AIDS movement, who can put on the pressure without fear of their funding being cut. We need a group like ACT UP to keep the game honest."

As Maxine Wolfe, a longtime community activist, warns, "If you're not continually out there, your gains slip away." Indeed, just this year, hundreds of doctors, scientists, and people with AIDS were barred from America's major AIDS science meeting. Activists are still fuming at this retreat from the hard-won right of patients to learn—without middlemen—the latest research on the disease that is killing them.

There are worse outrages. Despite an avalanche of evidence that needle exchange dra-

matically slows the spread of HIV and doesn't increase drug addiction, the federal government and New York City still refuse to fund such programs. The human cost of this neglect is horrifying: A recent study estimated that 10,000 U.S. HIV infections have been caused by the lack of needle exchange, 2300 of them in New York City.

Another key issue is the astronomical cost of the new protease-inhibitor cocktails—about \$15,000 per year. In some states, lack of government subsidies has meant that some patients cannot get the new drugs, and a proposed perpatient cap on Medicaid benefits threatens to cut off still more. Next week's demonstration will protest these outrageous prices, and demand—as ACT UP has for a decade—"treatment for all."

"I'm praying for people to reappreciate what ACT UP was," says Dennis deLeon, head of the Latino Commission on AIDS. "The whole AIDS establishment needs a big kick in the butt."

For information about the Wall Street demonstration and the conference that precedes it, call (212) 966-4873. ACT UP meets every Monday at 7:30 p.m. at the Gay and Lesbian Community Services Center, 208 West 13th Street.

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GOLDSTEIN

CONTINUED FROM PAGE 43 introducing themselves. But when they did, the floor erupted in applause. Says Chris, "That's when we knew we had done the right thing."

Indeed they had. Silence = Death became not only a slogan for AIDS activism, and a huge moneymaker for ACT UP (which held the copyright), but a symbol of resistance so potent even abortion activists have used it. Avram winces when he hears that ABC News chose "Silence Equals Acceptance" as the motto of its current series on drug abuse. "The culture neutralizes things," he sighs. "It neutralized us."

Still, it's no mean feat that, for six years, these artists eluded both censorship and commerce. They did it by working anonymously and polymorphously. In 1987, the Silence = Death Project disbanded as another group arose. They called themselves Gran Fury, after one of Detroit's tackier automotive creations. This campy homage fit a movement whose cadres sported names like Little Elvis or The Marys.

The members of Gran Fury had Uptown careers that taught them the methods of advertising, and Downtown connections that gave them access to conceptual art. Blending Barbara Kruger with Jerry Della Femina, they produced work that was rich enough for a gallery window and slick enough for a bus shelter. These pieces were highly effective at inserting a political message in political messa

sage in unlikely places. Sometimes too effective. In 1988, Gran Fury designed a poster to accompany an ACT UP kiss-in. The image of two sailors lip-locking had been lifted from vintage gay porn. But the text was prophetic: READ MY LIPS, it read, shortly before George Bush made those words his own. The combination was more than some people could bear, and the poster was defaced. That led Gran Fury to expand the theme, in a 1989 series meant to run on buses in various cities. Its image of multiracial, multisexual couples kissing injected a robust homoeroticism into the AIDS crisis at a time when most people wanted to think of gays as sick or dying.

The "AIDS Kiss Poster," as the Chicago press dubbed it, inspired a fevered resolution by the Illinois legislature banning any image that showed "physical contact or embrace within a homosexual or lesbian context where persons under 21 can view it." But the image ran in every Chicago daily. Gran Fury had learned something about piggybacking on bigotry. "We'd create this kind of incendiary device," says member Richard Elovich, "and it would keep going off."

Still, no one was prepared for what happened at the Venice Biennale in 1990. Gran Fury had been invited to participate, and its members created a work called *The Pope and the Penis*. It came in two parts: an erect dick bearing the slogan SEXISM REARS ITS UNPROTECTED HEAD, and a photo of the Pope with a text that acused him of preferring "living saints and dead sinners." Showing a penis was no problem in swinging Venice, but insulting the Pope was a real *scandalo*. Customs agents impounded the work.

"We heard that they had stored it in a pizza parlor," Richard recalls. "So we rented a gondola, sailed over to the shop, and stole our own work. Then we carted it over to our assigned space and put it up." The publicity upstaged even Jeff Koons's rendition of himself shtuping Ciccolina.

world. But the AIDS crisis had changed. More and more people of color were infected, creating new demands and issues of authority. "We spent months trying to figure out how to relate to all the different communities," Avram recalls. "Finally, we realized that our strategies were bankrupt." Other members see it differently. "There was a moment when I realized we had done our work," says Marlene McCarty, the only woman in Gran Fury. Donald Moffett describes "an empty bucket."

But Mad Ave found water in the well. After Bennetton borrowed the ACT UP look, it turned up everywhere. Kissing queers were selling Diesel jeans. Warner Brothers wanted to use Silence = Death in *The Pelican Brief*. "You can't control the way things mutate," says member Loring McAlpin. "And I guess it's flattering." Avram has a darker view of what went down: "We painted ourselves into a corner by being so clever and accessible and successful."

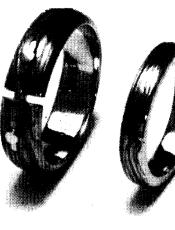
Gran Fury's last work went up in 1993. It was inspired by member Mark Simpson, who died just last December. On a sheet of white paper, four small lines addressed what the crisis had become: "Do you resent people with AIDS? Do you trust HIV negatives? Have you given up hope for a cure? When was the last time you cried?"

Maybe it's because he's lost two lovers to AIDS, or maybe it's his heritage as a red-diaper baby, but Avram still simmers with a blue flame of rage. He deeply resents "the normalization of AIDS," and he's haunted by the thought that Gran Fury helped to create that illusion. He thinks the optimism of its art had the unintended effect of quelling people's rage, just as its image of the plucky homosexual has lulled queers into thinking they have overcome. "I wear this earring with a skull on it," Avram says. "I used to think I'd take it off when the AIDS crisis ends. Now I think I'll wear it all my life."

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